

Commentary

Health care disparities in children with rheumatic diseases

Karen Onel, MD and Charles H. Spencer, MD
University of Chicago/La Rabida Children's Hospital
Chicago, IL.

In an ideal world, we would want all our children with rheumatic disease to have access to pediatric rheumatologists for optimal care with the best drugs and with an equal chance of doing well. In reality, health care disparities, i.e., differences in the availability and access to health care, optimal treatment, and a good prognosis, persist. These disparities appear to correlate with ethnic, socioeconomic, and political realities in many countries, including the United States. We would like to review recent studies regarding access to medical care for adults and children and see how this issue may relate to our population of children with rheumatic diseases.

Adult disparities

In the US, some ethnic minorities, e.g., the Hispanic, African-American, and Native American populations have been found to have a higher prevalence of arthritis than other ethnic groups in the US [1-2]. These individuals also may experience more limitations of daily activities due to arthritis than Caucasians. [3] African-Americans with osteoarthritis have been found to be less likely to be prescribed narcotic analgesic medications than are Caucasians. [4] Rates of knee or hip arthroplasty are also lower in Hispanics and African-Americans than Caucasians in the US. [5] Lower rates of surgery for African-Americans have been partly attributed to a more global tendency to avoid surgery, perhaps due to a lack of certainty of benefit versus risk. These differences in care extend across many countries. In the United Kingdom, rates of hip arthroplasty are lower in individuals with low socioeconomic status. In Australia, women and those of lower socioeconomic status awaiting hip arthroplasty had longer waiting times, suffered with a more severe compromised quality of life and had severe psychological distress compared to population norms [6-7]. Clearly, being poor and in a minority group may translate to poorer health care.

Disparities in SLE are noteworthy. Several studies have suggested that severity of SLE may be positively correlated with poverty and ethnicity. [8-9] Also, a lower socioeconomic status may increase the risk for lupus mortality. [10] Compliance has been shown to be similar in Caucasian and African-Americans, though the barriers to compliance may be different. [11] The ultimate health disparity is the mortality rate of different ethnic groups. In the US, Caucasians live longer than African-Americans and Hispanics. [12] The causes are no doubt multifactorial but one factor appears to be disparities in health care.

Pediatric disparities

Not surprisingly, health care disparities are all too present in the health care available for children. Children generally have less power and are less valued than adults since they do not vote or work and their medical care can take second place to the care of adults. Poor children are often marginalized and, compared to wealthier persons, have limited resources for health care, and especially for medications. In the US, access to care for vulnerable children remains an issue. A study on physician access and distribution in Washington, DC, documented major racial and socioeconomic medical care disparities with limited access to care in poor, inner city areas, despite an abundant supply of primary physicians in the DC area. [13] There are disease-specific disparities that have been noted. Children with asthma have been studied in several populations. In the Medicaid population in Boston, African-American and Hispanic children have a worse asthma status and use less preventive asthma medications than their Caucasian counterparts. [14]

Systemic disparities

There are many health care disparities that appear to be related to how medical systems function in different countries. Some examples include:

- 1) Rich-poor duality and its effect on medical care.
- 2) Medical insurance—State or Private.
- 3) Access to physicians.
- 4) Lack of planning in medical systems.

Rich-poor duality

There is no doubt that most countries, including the US, have a two-tiered system in which wealthier individuals and families often receive better health care overall than the poor. The individuals with sufficient economic means go to private hospitals and pay for the best medical care that their country can offer, including expensive new technology and drugs. They may seek health care in other countries if needed procedures are not available at home.

In contrast, the poor and some of the middle class must mostly rely on the public, governmental hospitals or lesser private institutions where care and compassion may be abundant, but beds, amenities, physician time, medications and technology may be limited. The private hospitals are run by private practitioners and the public hospitals by less experienced residents with some guidance but often limited supervision from attending physicians. Quality of care may be an issue. The public hospitals have limited resources and very basic drug formularies. Poor patients may not have access to newer, perhaps better medications and technologies. They may borrow money from relatives and friends to purchase an expensive medication for a limited time but it is often only a temporary help. Limitations of money for transportation, inability to take off from work, preference of local traditional health alternatives, lack of understanding of the medical problems and cultural issues all may present obstacles to what we believe is the best care.

Medical insurance

The medical insurance system varies from country to country. In the United States medical

insurance is largely organized as a for-profit enterprise. The paradigm is to keep health care expenditures down to maximize profit for the insurance company. This may often lead to conflict between what a physician orders and what the insurance will pay for, and thereby reduce trustworthiness in both. [15] What the physician considers standard of care and the best treatment may not be possible due to insurance constraints. For patients with rheumatoid arthritis, managed care has been associated with the lowest usage of biologic agents and DMARDs compared to traditional indemnity insurance plans. [16] Continuity can be sacrificed if insurance coverage changes, and the patient must transfer care to another physician or center. This is especially true for children in the foster care setting. [17] Patients with chronic illness may be especially vulnerable under for-profit managed care plans. One study reported that chronic illness was associated with increased odds of dissatisfaction in both independent practice association plans and prepaid group practices, but not under fee-for-service coverage. [18] However, insurance may allow the rheumatologist to provide aggressive state-of-the-art care to his/her patient that may not be possible otherwise. The expensive medications may be affordable only with an insurance plan. [19] Insurance is then a double-edge sword. It can help pay for medical care, but can also limit drugs available and medical care based upon profit rather than true medical need.

Access to physicians

The Holy Grail is the perfect ratio of patients to physicians with every adult and child having speedy access to excellent medical care, both primary and specialty. This appears to be a problem everywhere. The one exception may be for the wealthy. No matter what country, wealthy individuals or families can often find the best medical care in their country or elsewhere. This is rarely true for poor children or adults. Although they may live in a city and may be able to travel to large government hospitals, these facilities may or may not have all the needed primary care physicians and specialists. Conditions may not be as good as in private hospitals and waits may be long. Greater problems may exist in rural areas. [20-21] People living in the rural areas may need to travel far distances to seek medical advice. Physicians of all specialties may be less available. The most readily available care may be traditional care which may be variable in quality. Children with serious complex illnesses, such as arthritis, cancer or diabetes, may not be easily helped by traditional care and it may take longer, if ever, to get to the appropriate medical care. The prognoses of these children may be adversely affected.

Lack of planning in medical systems

In the US we may be only too aware of the effect that inadequate national medical planning has on access of care. The government and pediatric organizations at times favor trusting "market forces" to provide the subspecialty care needed for children with chronic illness. These groups pushed primary care 15 years ago to the detriment of subspecialty development. Although the subspecialty system in the US is better developed than in many countries, the need for subspecialty care in pediatrics far outstrips the supply of subspecialists. Access to care for many subspecialties is so limited that in some areas the wait for a new appointment may be 6-12 months unless the patient is in crisis. Parents are aggressively

seeking subspecialists via the internet. [22] General pediatricians could fill the gap if they had the training and the time. The solution most commonly suggested is that internal medicine subspecialists care for these chronically ill children despite the fact that many of these practitioners have not been adequately trained to care for these special children and adolescents and their diseases. The therapy pathways used to treat adults may be inappropriate for children, even with the same complaints. [23]

The overall lack of planning in medical systems may aggravate health disparity problems as well. The maldistribution of physicians can contribute to variations in health care. With no incentive to do otherwise, specialists may choose to practice where they can make more money rather than where they can have the most impact. [24] This is especially true considering the debt-burden for young medical school graduates and the relatively low salaries provided by academic medical centers.

What does this have to do with pediatric rheumatologists?

It has to do with our patients. Patients of one ethnic or socioeconomic group may do worse with a certain disease (e.g., lupus or JIA) than other patients. [25] With these many problems creating disparities, we are unable to provide the optimal care our children need, whether they are rich, poor, or in-between. At first glance, these problems may appear intractable and unsolvable. Why waste our time on things we cannot change? But we can start with several steps:

- 1) Acknowledge that there are often serious disparities in health care.
- 2) Reflect on how these disparities may hurt our patients.
- 3) Consider whether the current status quo in our countries is acceptable and whether we can do better.
- 4) If we agree that the status quo is not acceptable, we should do what we can within each of our health systems, hospitals, and individual practices to diminish any disparities we see.
- 5) Each of us must give each child with rheumatic disease the best health care possible regardless of income, social status or ethnic group. This means showing no preference for, or providing a different level of care to, wealthy or well-connected patients and patients with the best resources, contacts, or insurance. It is necessary to acknowledge that some "rich versus poor" differences are unavoidable if medications must be paid for.
- 6) We should consider working to make the new biologics and other expensive new break-through treatments available to everyone, regardless of income or status.
- 7) Lastly, we need to study these health disparities, further document their prevalence, and demonstrate how these disparities impact different health outcomes. Documenting these differences in publications may help us persuade influential individuals in our health systems to begin a process of change.

Health care disparities are present and no doubt, some are not easily fixed. Yet we should expose them to the air, discuss them, and work to gradually eliminate them.

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